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## ABSTRACT

Parents of children with mental or physical handicaps often experience overwhelming feelings of stress and anxiety. Research indicates that support for the primary caregiver can help alleviate some stressors involved in raising a child with a handicap. This study examined how level of support affects feelings of satisfaction the primary caregiver has when raising a Down Syndrome child. It was hypothesized that the caregiver's positive feeling of satisfaction would correlate positively with level of support found within the informal support system (family, relatives, friends) and level of utilization of the formal support system (doctors, teachers, support groups). It was also hypothesized that the informal support system would be more beneficial than formal networks of support. Data were collected using a 35-item questionnaire from a national sample of 82 volunteers and were analyzed using a one-way analysis of variance and correlational techniques. A significant correlation was found between positive feelings of satisfaction and both informal support formal support. However, the informal support system was not found to be more beneficial. These findings indicate that help from any level of ecological influence may have positive effects on primary caregiver's feelings of satisfaction. Contains 24 references. (Author/JBJ)

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EFFECTS OF SUPPORT ON THE ATTITUDE OF THE PRIMARY CARE GIVER OF A CHILD WITH DOWN SYNDROME

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## Abstract

### Effects of Support on the Attitude of the Primary Caregiver of a Child with Down Syndrome

Parents of children with mental or physical handicaps often experience overwhelming feelings of stress and anxiety. The birth of a Down Syndrome child may demand a completely new lifestyle for the parents and siblings of the child, but especially for the primary caregiver. Research indicates that support for the primary caregiver can help in alleviating some of the stressors involved in raising a child with a handicap. This study looked at how the level of support affects the feelings of satisfaction the primary caregiver has when raising a Down Syndrome child. In this study it was hypothesized that a positive feeling of satisfaction by the primary caregiver of a Down Syndrome child would correlate positively with the level of support found within the informal support system (family, relatives, and friends) and the level of utilization of the formal support system (doctors, teachers, support groups, etc.). It was also hypothesized that the informal support system would be more beneficial and have more positive effects on the primary caregiver than the formal networks of support. Data were collected using a 35-item questionnaire from a national sample of 82 volunteers and were analyzed using a one-way analysis of variance and correlational techniques.

The Pearson correlational coefficient test was used to test the validity of the three hypotheses. A significant correlation was found between the positive feelings of satisfaction and informal support and the positive feelings of satisfaction and formal support. However, the informal support system was not found to be more beneficial or have more positive effects on the primary caregiver than formal networks of support. These findings indicate that help from any level of ecological influence whether, formal or informal, may have positive effects on the feelings of satisfaction of the primary caregiver of a Down Syndrome child.

## Chapter 1

### Introduction

Parents of children with mental or physical handicaps often experience overwhelming feelings of stress and anxiety. These parents are subject not only to the pressures and tensions faced by the parents of non-disabled children, but also to the unique challenges and experiences associated with parenting a child with a disability (Petersen, 1983).

The addition of a new family member has been described as a crisis, a critical event, and a period of transition. Most investigators agree that the birth of a child with a disability greatly magnifies and confounds the situation (Riper & Selder, 1989). The birth of a disabled child also introduces great change into the family. These changes often require coping and adjustment.

Literature suggests that parents experience unique child-rearing challenges at each stage of development related to such issues as child autonomy and the educational process, particularly when a child is handicapped. Parents of children with Down Syndrome not only deal with the roles and developmental tasks at hand, but they also must deal with the additional acute and chronic stresses involved in raising their child (Haldy & Hanzlik, 1990). The birth of a Down Syndrome child may demand a completely new lifestyle

for the parents and siblings of the child, but especially for the primary caregiver. Research indicates that support for the primary caregiver can help to alleviate some of the stressors involved in raising a child with Down Syndrome (Dunst, 1985).

Support over time has been variously defined. For the purpose of this study, support will be defined as one giving strength to, enabling one to continue, assisting someone by one's approval or presence, and/or one taking a secondary part. Support systems may be the material or emotional attentions given by others or personal resources, such as specific skills or high self-esteem (Goldberg, Marcovitch, MacGregor, & Lojkasek, 1986).

There are two types of support systems which may be utilized by the primary caregiver if made available. These are referred to as formal and informal networks of support. Formal support systems involve all types of community and social services such as support groups, health professionals, educational services, etc. Informal support systems refer to the immediate or nuclear family, the extended family, and friends. The community and family assist in giving support to the primary caregiver of a Down Syndrome child by providing emotional as well as physical support.

One of the aims of the present study is to investigate the effect of formal and informal support systems on the

primary caregiver. By way of looking at each network of support individually, this study will then analyze which support system has the most positive effect on the primary caregiver overall.

#### Formal Support Systems

A study by Donna Spiker (1982) found that mothers reported beneficial emotional support from parent group meetings during the infancy period of their Down Syndrome children. These mothers also described, as the most helpful aspects of the group meetings, the emotional support from talking and sharing feelings with other parents and the specific information about Down Syndrome, child development, and techniques to promote development. In a study by Erickson and Upshur (1989), mothers of infants with Down Syndrome reported significantly greater satisfaction with their infants with support from community groups than did a comparison group of mothers without these support systems.

In a study that reduced uncertainty by the comparison of oneself with others in similar circumstances, a process known as cohort comparative testing, Riper and Selder (1989) found that the opportunity to meet and talk with other parents of children with Down Syndrome was very helpful to parents. By the sharing of experiences with others in similar circumstances, these parents were able to validate their feelings and concerns.

Hanson and Hanline (1990) found that the types and availability of formal systems and networks of support contribute to family adaptation. They suggest that personal coping resources and social support systems can be crucial for families of individuals with developmental disabilities. They also found that parental satisfaction with support and the number of sources of support have been shown to be positively related to family integrity, parental perceptions of child functioning, parent-child play opportunities, and child behavior and outcome.

In a study on the adaptation of families with mentally retarded children, Crnic, Friedrich, and Greenberg (1983), it was found that social networks involve potentially supportive relationships that may facilitate positive adaptations. They found that social support available from several sources has a positive impact on parental functioning. They also found that parents who utilized more support networks were more supportive of mainstreaming and parents who had less support were more isolated.

Rhodes and Gillies (1985) surveyed parents' use of and satisfaction with the services available for families with preschool Down Syndrome children, services from health and educational professionals. Findings showed that the majority of families considered the Teacher Counselor to be very important in helping them to bring up their handicapped child. These families indicated that the Teacher Counselor

had given them a great deal of advice and information relevant to the syndrome. The counselor also acted as a liaison with other services by putting parents in touch with self-help groups, advising on schools, providing literature, and discussing the future of the child. Almost all of the families had been visited by a health professional. Although parents were largely happy with the health visitors contribution, the majority of these parents attached little or no importance to her contribution in helping to bring up their handicapped child.

In a study by Seltzer and Krauss (1989) on aging parents with adult mentally retarded children, it was reported that an adequate social support network can enhance the physical health, mental health, and longevity of the elderly caregiver and buffer the effects of stress. Also, they suggest that formal services enable families to continue to care for a dependent member because services improve the well-being of caregiving families.

A study by Crnic, Friedrich, and Greenberg (1983) found that social support appears to be a meaningful ecological variable influencing parenting attitudes, mother-child interaction, and infant development. They suggest that social support from various sources facilitates more positive child-rearing attitudes, as well as more positive behavioral interactions. Cochran and Brassard (1979) also suggest that social support networks influence parents'

attitudes and behavior and have direct and indirect effects on the child's development. Mueller (1980) suggests that social support serves as a buffer against the experience of stress and also posits that social support has independent influences on behavior and attitudes.

Social system theory postulates that social networks and the support that members provide both directly and indirectly influence the behavior, attitudes, expectations, and knowledge of parents and their offspring. By using the systems theory as a conceptual framework for assessing the effects of social support, Dunst, Trivette, and Cross (1986) found that social support has a positive effect on personal well-being and on such a potentially devastating event as the birth and rearing of a handicapped child. They also found that for the overprotective parents of a handicapped child, if the parents had network members that were helpful with regard to the care of their child, such help mediated the degree to which the parents felt it necessary to overcompensate by sheltering their child. Through research, they found that social support is a multidimensional construct that includes physical and instrumental assistance, resource and information sharing, and emotional and psychological support. Furthermore, they found that there is general consensus among social systems theorists that social support networks function to nurture and

maintain linkages among persons who are supportive on both a day-to-day basis and in times of need and crisis.

#### Informal Support Systems

Sloper, Knussen, Turner, and Cunningham (1991) found that the marital relationship has supportive functions in relation to parenting, particularly to the wife's morale and sense of competence as a mother. Thus, they suggest the need to include fathers in intervention programs concerned with family functioning and child development. They also found that social support was mediated by factors internal to the parent and family. They suggest that social support may be a function of personality and that intra-family support has greater influences on stress than social support.

Another study by Damrosch and Perry (1989) documents the importance of husbands in providing support to mothers of Down Syndrome children. They reported that these mothers listed spouses as the most important of 19 possible support persons. Also, marital satisfaction was the best single predictor of the coping of the mothers. They found that fathers of retarded infants and children tend to have a low level of participation in caregiving. They suggest that the father's most powerful influence on the child may operate indirectly by affecting the mother's ability to cope, as well as her childcare attitudes and behaviors, thus the

father may play a key role in setting the pattern for the child's acceptance or rejection in the home.

Friedrich (1979) also found that the mother's report of marital satisfaction had the greatest bearing on her reported capability in caring for her handicapped child. And Crnic, Greenberg, Ragozin, Robinson, and Basham (1983) reported findings that marital support affects parents' perceptions of the difficulties of rearing a developmentally disabled child. Belsky (1981) reported that a positive marital relationship is a major support of competent parenting. She found that intimate support provided more global positive effects than either friendship or community support. She suggested that the immediate availability that intimate support provided to mothers with a handicapped children is likely a function of its proximity, as well as the probability that families spend less time in outside social activities with friends and community groups, and more time together as a family unit.

Friedrich, Wiltturner, and Cohen (1985) found that marital satisfaction was a significant predictor of good coping skills for the parent of a handicapped child along with marital happiness and a positive family social climate. Goldberg et al. (1986) found that mothers of handicapped children who received more support from both sets of grandparents reported more positive coping experiences. Erickson and Upshur (1989) found that mothers of infants

with Down Syndrome reported more satisfaction in rearing their handicapped children with the support of friends. Johnson and Sarason (1978) suggest that mothers who are depressed and do not feel supported in their marriages or by their friends and family are going to be less able to reinforce appropriate behavior in their disabled children than are mothers who are not depressed and are involved in several supportive relationships. And Minnes (1988) found that support from extended family, friends, and neighbors for the mother of a handicapped child was positively related with lower levels of stress associated with more personal reward.

A study by Haldy and Hanzlik (1990) found that mothers who were satisfied with their family support systems felt more competent than those who were dissatisfied. In addition, their findings indicated that the more satisfied the mothers felt with the help they received in caring for their children from family members, the more competent they felt. They suggest that the day-to-day parenting tasks and roles become more cumbersome than the emotional issues at hand and are made easier with the type of support that permits the sharing of child-rearing tasks.

From the study on aging parents with adult mentally retarded children by Seltzer and Krauss (1989), it was found that the well-being of caregiving mothers pertained to the importance of the family social climate, which emerged as

the strongest domain of support. They found that for these women, the parenting role remains a central part of their identity and continues through old age. Furthermore, they suggest that dimensions of the family social climate, including the relationships among family members, the value orientations of the family, and the organization of the family, may be more salient for older women with an adult retarded child than for their age peers.

Minnes (1988) suggests that family resources such as the personal resources of individual family members, the internal or systemic characteristics of the family that contribute to its role structure and organization, and the support received from extended family and friends play an important role in family adaptation to the stressor events associated with having a mentally retarded child. And because there is evidence that some mothers of retarded and physically disabled children are socially isolated, Friedrich and Friedrich (1981) suggest that these mothers may be more vulnerable to stress if they do not receive support from other sources such as the immediate family.

Schilling, Kirkham, Snow, and Schinke (1986) found that single parents of handicapped children have less extensive social networks than married persons. They reported that single parents have less time and fewer opportunities to join self-help organizations or support groups. These findings might suggest that if the primary caregiver is not

receiving support from his/her informal support systems such as the spouse, then, just as the single parent, he/she will have less time and fewer opportunities to participate in more formal support systems.

Finally, in a study on the mediating influences of support for the caregiver of a handicapped child, Dunst et al. (1986) found that satisfaction with intra-family role sharing was related to the intrapersonal, physical and emotional well-being of the caregiver. They suggest that family integrity is related more to certain types of informal support rather than to support in general.

#### Present Study

The present study will look at formal and informal networks of support. The primary purpose of this study is to evaluate which support system is the most beneficial and has the most positive effects on the primary caregiver of a Down Syndrome child.

#### Hypotheses

Hypothesis I. A positive feeling of satisfaction as the primary caregiver of a Down Syndrome child will correlate positively with the level of support utilization in the informal support system.

Hypothesis II. A positive feeling of satisfaction as the primary caregiver of a child with Down Syndrome will correlate positively with the level of utilization of the formal support systems by the caregiver.

Hypothesis III. The informal support system is more beneficial and has more positive effects on the primary caregiver of a Down Syndrome child than formal networks of support.

## Chapter 2

### Methods

#### Subjects

Eighty-two volunteer subjects were recruited from the National Down Syndrome Parents' Association Conference in Anaheim, California. These participants gave this study a nationwide sample. Each participant had to be the primary caregiver of a Down Syndrome child. Eighty data sets, all completed by women, were included in the analysis of the hypotheses of this thesis. The other two, the only surveys completed by men, were deleted due to these data sets possibly skewing the results. Ages of the participants ranged from 20 to 49 years.

#### Materials

Data were collected from a survey completed by the primary caregiver of each family. The survey was in the form of a 35-item questionnaire (see Appendix C). These questions were used to measure the informal support systems of the primary caregivers, the formal support systems of the primary caregivers, and the positive feelings of the primary caregivers. Included with the questionnaire was an instruction/informed consent page (see Appendix B).

#### Procedure

Participants were given the survey and asked to answer the questions individually (see Appendix B for detailed

instructions). It took participants approximately 10 to 15 minutes each to finish the survey. Although subjects were asked to sign the informed consent page on the questionnaire, anonymity was protected. The subjects were advised of their rights as anonymous volunteers according to American Psychological Association ethical standards. When the completed questionnaires were collected, the answer sheets were removed and shuffled into a stack of identical answer sheets. The answer sheets were computer coded and scored.

Data were analyzed using a one-way analysis of variance and correlational techniques. The results are discussed in the next chapter.

## Chapter 3

### Results

Data were collected using the survey in Appendix C. Questions 1 - 10 were used to measure the informal support systems (e.g., nuclear family, extended family, friends, neighbors) of the primary caregiver. Questions 11 - 17 were used to measure the formal support systems (e.g., support groups, doctors, teachers) of the primary caregiver. Positive feelings of satisfaction (e.g., high self-esteem) of the caregiver were measured in questions 18 - 24.

Of the 82 primary caregivers who participated in the study, only two participants were men. The decision was made to eliminate the two male scores, because extreme scores often skew results.

A one-way analysis of variance was used to compare the informal support system, the formal support system, and the positive feelings of satisfaction of the primary caregivers on each demographic variable.

Within the informal support system, Table 1 shows that the age group, 40 - 49 years, differed significantly from all other age groups,  $F(2,79) = 3.9753$ ,  $p < .0227$ . The 40 - 49 year-old group received more support from within the family than any other age group. Marriage played a role in the amount of informal support the primary caregiver received. Table 2 shows that a significant difference was

Table 1

ANOVA Summary Table for Informal Support Systems and Age  
Groups

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	df	Mean Squares	F
Age Group (40-49)	2	578.001	3.9753*
	77	145.397	
Total	79		

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\*p < .05

Table 2

ANOVA Summary Table for Informal Support Systems and Married  
Groups

	df	Mean Squares	F
Married Caregivers	1	2864.865	23.555**
	78	121.624	
Total	79		

\*\*p < .01

found between the married and single primary caregivers  $F(1,79) = 23.5551, p < .0001$ , with married caregivers receiving more support than single caregivers. Table 3 shows that the primary caregivers of families with incomes of \$49,999 or less received significantly less support than families with incomes between \$50,000 and \$100,000,  $F(3,79) = 3.1178, p < .0310$ .

Within the formal support system, Table 4 shows that the age group 40 - 49 years, again differed significantly from all other age groups,  $F(2,79) = 3.7634, p < .0276$ , receiving significantly more support than any other age group. Table 5 shows that married primary caregivers received significantly more formal support,  $F(1,79) = 18.4546, p < .0001$ , than single primary caregivers. Table 6 shows that primary caregivers of families with incomes between \$50,000 and \$100,000 differed significantly in the amount of formal support they received from primary caregivers of families with incomes of \$49,999 or less,  $F(3,79) = 2.9475, p < .0381$ . The higher income families appeared to be able to utilize more formal support systems than the families with lower incomes.

When measuring the level of positive feelings, Table 7 shows that the age group 40 - 49 years, significantly differed from all other age groups,  $F(2,79) = 4.0476, p < .0213$ . The age group 40 - 49 years, reported much higher positive feelings of satisfaction than all other age

Table 3

ANOVA Summary Table for Informal Support Systems and Income

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	df	Mean Squares	F
Income between \$50,000 & \$100,000	3	451.179	3.118*
	76	144.712	
Total	79		

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\*p &lt; .05

Table 4

ANOVA Summary Table for Formal Support Systems and Age  
Groups

	df	Mean Squares	F
Age Group (40-49)	2	250.824	3.7634*
	77	66.648	
Total	79		

\*p < .05

Table 5

ANOVA Summary Table for Formal Support Systems and Married  
Groups

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	df	Mean Squares	F
Married Caregivers	1	1077.863	18.455**
	78	58.406	
Total	79		

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\*\* $p < .01$

Table 6

ANOVA Summary Table for Formal Support Systems and Income

	df	Mean Squares	F
Incomes between \$50,000 & \$100,000	3	195.716	2.946*
	76	66.400	
Total	79		

\*p &lt; .05

Table 7

ANOVA Summary Table for Positive Feelings of Satisfaction  
and Age Groups

	df	Mean Squares	F
Age Group (40-49)	2	291.930	4.0476*
	77	72.125	
Total	79		

\*p < .05

groups. Table 8 shows that married caregivers also reported significantly higher positive feelings of satisfaction than single caregivers,  $F(1,79) = 23.3025, p < .0001$ . Families with higher incomes appeared to play a role in positive feelings of satisfaction of the caregivers as well. Table 9 shows that caregivers from families with incomes of \$50,000 - \$100,000 reported significantly higher positive feelings of satisfaction than caregivers from families with incomes of \$49,999 or less,  $F(3,79) = 3.0012, p < .0357$ .

The Pearson correlation coefficient test was used to test the validity of the three hypotheses. Hypothesis I stated that a positive feeling of satisfaction as the primary caregiver of a Down Syndrome child will correlate positively with the level of support found within the informal support system; and, Hypothesis II stated that a positive feeling of satisfaction as the primary caregiver of a child with Down Syndrome will correlate positively with the level of utilization of the formal support systems by the caregiver. The level of positive feelings of satisfaction of the primary caregivers was compared to the level of informal support and the level of utilization of formal support. A significant correlation was found between the positive feelings of satisfaction and formal support ( $r = .99, p < .0001$ ) and the positive feelings of satisfaction and formal support ( $r = .98, p < .0001$ ),

Table 8

ANOVA Summary Table for Positive Feelings of Satisfaction  
and Married Groups

	df	Mean Squares	F
Married Caregivers	1	1411.801	23.303**
	78	60.586	
Total	79		

\*\*p < .01

Table 9

ANOVA Summary Table for Positive Feelings of Satisfaction  
and Income

	df	Mean Squares	F
Income between \$50,000 & \$100,000	3	216.697	3.001*
	76	72.203	
Total	79		

\*p < .05

therefore Hypothesis I and Hypothesis II were both accepted. Due to the informal support system not being found to be more beneficial and not having more positive effects on the primary caregiver of a Down Syndrome child than formal networks of support (as stated in Hypothesis III), Hypothesis III was rejected.

## Chapter 4

### Discussion

According to the results of this study, certain demographic variables did play a role in influencing the primary caregivers. The age group 40 - 49 years, the oldest age group to participate in this study, reported receiving more support, whether formal or informal, than any other age group. Higher support appears to be positively related to the caregiver's positive feelings of satisfaction; this age group reported higher positive feelings of satisfaction than any other age group. Married caregivers reported significantly more formal and informal support systems than singles and reported higher feelings of satisfaction as caregivers. Finally, income had a direct effect on the caregiver. Primary caregivers from higher income families reported more formal and informal support and reported higher positive feelings of satisfaction.

The three hypotheses tested using the Pearson correlation test were: (a) a positive feeling of satisfaction as the primary caregiver of a Down Syndrome child will correlate positively with the level of support found within the informal support system; (b) a positive perception of oneself as the primary caregiver of a child with Down Syndrome will correlate positively with the level

of formal support systems that are utilization of the by the caregiver; and (c) the informal support system is more beneficial and has more positive effects on the primary caregiver of a Down Syndrome child than formal networks of support. Because a significant correlation was found between positive feelings of satisfaction and informal support, and positive feelings of satisfaction and formal support, both Hypotheses I and II were supported. However, as stated earlier, there were no significant differences found between formal and informal support systems; therefore, Hypothesis III was rejected.

Further research might examine the reason as to why certain demographic groups differed significantly in the amount of support they received. This researcher's assumption is that married caregivers naturally have another person who may offer physical as well as emotional support. Also, married caregivers probably have a larger formal support network due to the fact that they can get out more easily and leave the child or children at home with their spouse. As for the age group 40 - 49 years, which was the oldest age group to participate in this study, this researcher speculates that the older age groups are probably more demanding of help whether from the family or from outside resources. Older age groups are usually more knowledgeable due to experience and will often have a preconceived set of standards and expectations and perhaps

be more willing to ask for support. Both married and older age groups in this study appear to have more support; they also report higher positive feelings of satisfaction as caregivers of Down Syndrome children.

Other research might take a closer look at the differences between formal and informal support groups. This researcher felt that the closer proximity of the family or the informal support group would prove to be much more beneficial to the positive feelings of satisfaction of the primary caregiver; however, the results did not support that hypothesis. Because this study did not differentiate between the influences and the results, another study might examine how the subjects were influenced before they took this survey and also look at what these influences were.

In conclusion, these findings suggest that help from any level of ecological influence, whether formal or informal, may have positive effects for caregivers of Down Syndrome children. This framework of support may provide the caregiver with information to support the belief that he or she is cared for, valued, and a member of a network of mutual obligation, allowing the individual to feel good about him- or herself as the primary caregiver of a Down Syndrome child.

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